

REPORT TO THE GOVERNOR ON THE QUALITY OF CARE IN MASSACHUSETTS

February 1995

*A Report to Governor William F. Weld from the Governor's Commission on
Mental Retardation*

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The Commonwealth of Massachusetts

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GOVERNOR'S COMMISSION ON MENTAL RETARDATION

REPORT TO THE GOVERNOR

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In your letter of May 10, 1994 to the Governor's Commission on Mental Retardation, you requested an "analysis of systemic issues and problems affecting the quality of facility and community-based programs." You expressed particular interest in changes that have taken place since the end of the federal consent decree. During our meeting with you on June 15, 1994, you also requested that we place contemporary issues within an historical framework. This report has been prepared to address your questions and concerns.

Specifically, the report describes:

1. major changes in the system of services for persons with mental retardation over the last 30 years,
2. comparisons of the MA system to other states ,
3. major changes in the system of services in Massachusetts since the federal court disengagement order, and
4. issues affecting the quality of services in Massachusetts .

I. MAJOR CHANGES IN THE SYSTEM OF SERVICES FOR PERSONS WITH MENTAL RETARDATION IN THE LAST 30 YEARS

By any standard of analysis, there has been a sea-change in the system of services for persons with mental retardation since the 1960s. An adult with retardation in the early 1960s would find virtually no community-based residential programs and only a smattering of sheltered workshops where the daily routine was characterized by highly repetitive activities for which pennies per week would be earned. Professional opinion was typically dismal regarding the potential of persons with mental retardation. An adult with mental retardation in 1994 faces a dramatically different life course, exemplified by a range of community-based residential options, supported and competitive employment opportunities, social and recreational programs, and a broader array of therapeutic services available regardless of age.

From a national perspective, the last 30 years have witnessed a variety of major advances and changes in the lives of persons with mental retardation and the state and local service systems that support them, including:

- A substantial increase in the life expectancy of persons with mental retardation, attributable both to the fruits of basic and applied research and to accumulated experience about their developmental potential and personal vitality across the life span

- The recognition that mental retardation is not solely or even primarily a "medical" condition, but rather a condition of diverse origins defined by difficulties in learning and social competence
- The creation of a comprehensive array of community based services (including health care, social, educational, habilitative, vocational, and residential) and supports which can enhance individual functioning and life opportunities
- Dramatic improvements in the quality of life and services available in state supported institutional facilities
- The diminished use of state supported institutional facilities and, in most states, efforts to close such facilities
- The enumeration of the rights of persons with retardation, particularly those for treatment, education, freedom from harm, and the right to live and work in settings to achieve a good quality of life
- Fundamental changes in societal, familial, and professional expectations of the capacities of persons with mental retardation to be included as members of their families or in communities throughout their lives
- Significant increases in the availability of federal funds for the support of persons with mental retardation, and the development of partnerships between state and federal authorities in the creation and support of a broadly conceived service system

What accounts for these changes? There is little dispute that the lion's share of the credit belongs to families and advocates of persons with mental retardation who have relentlessly articulated and fought for the opportunities of their children or family members with retardation to access educational, medical, and social services.

Credit is also given to the courts, which were called upon to redress an intolerable system of abuse and neglect in state operated public facilities that came to public light in the 1960s and 1970s. In the absence of effective leadership within the executive and legislative branches of state governments to ensure humane conditions and treatment, the federal courts required states across the country to guarantee basic rights and standards of care.

Credit is also given to expanded scientific and professional initiatives to understand the causes of retardation and to develop effective treatment and service strategies to capitalize upon and enhance the potential of persons with retardation to be active learners and contributors to society

Credit is also given to the legions of human service workers at all levels who were and are fueled

by passionate beliefs in the rights of persons with retardation to share community resources and to be visible and welcomed members of our communities.

Credit is also given to enhanced federal and state initiatives to ensure basic income support, housing opportunities, therapeutic services, and medical care increasingly available in communities throughout the country.

Despite public attention to the functioning of institutional and community based residential facilities that exist across the country, it is a fact that, both currently and historically, no more than 15% of the population with retardation has ever lived in a licensed residential setting (either institutional or community based). The vast majority live with their families or in their local communities. The passage of 30 years has not changed this fundamental reality. What has changed is the role of state and federal governments in the provision of community-based services and supports to the millions of persons with mental retardation who live in every community in this nation.

In summary, there are now expectations on the part of people with mental retardation, their families, and the professional community that inclusion, community participation, responsive services, and the protection of legal rights should characterize the context for living for persons with mental retardation.

II. HOW DOES MASSACHUSETTS COMPARE WITH NATIONAL TRENDS IN THE SYSTEM OF SERVICES FOR PERSONS WITH MENTAL RETARDATION?

The most commonly used data on which inter-state comparisons are made are available from the University of Minnesota and the University of Illinois-Chicago. Among the findings from these sources are:

- The reduction in census of the MA state facilities since 1980 is near the national average (42.3% reduction in MA; 45.5% reduction nationally). 26 states surpassed MA in the reduction of their institutional census during this period.
- The utilization of small (1-6 person) community residences in MA is less frequent than the national average (34.8% in MA; 44.4% nationally).
- MA ranks 2nd in the country in the per diem rate for institution care.
- With respect to the Home and Community Based Waiver Program, MA ranks 5th in the country in number of participants and ranks 5th in the country in waiver services funding.

There have been no national studies comparing the quality of services delivered across the 50 states. One recent study compared MA to two "comparable" states (MI and MN) and described a variety of issues in which MA was viewed as less innovative and more bureaucratically dominated than the comparison states (Mental Retardation Programs: How Does Massachusetts Compare? by Edward Moscovitch, Ph.D. for the Pioneer Institute for Public Policy Research).

III. MAJOR CHANGES IN THE SYSTEM OF SERVICES IN MASSACHUSETTS SINCE THE FEDERAL COURT DISENGAGEMENT ORDER

On May 25, 1993, Judge Joseph Tauro signed a Disengagement Order which ended twenty years of federal court supervision of the Department of Mental Retardation (DMR). In his final order he wrote that *"Defendants shall continue to seek to improve, and shall not undermine, the progress achieved during the period of this litigation."*

The event signaled a long sought victory for the DMR. At the same time, the event was a moment of extreme concern for those parents and friends of persons with mental retardation whose lives had enjoyed unique protection under the federally governed consent decrees. While the DMR professed its commitment and capability to operate independently a high quality system of services for all persons with mental retardation, members of the various plaintiff groups professed deep skepticism that the benefits accrued over 20 years of federal court supervision would be maintained. Other constituencies, most notably parents of adults with retardation living in the community, hoped that there would be increases in funding for the community based system of services. It was clearly hoped that it was now, finally, their turn for services.

By all accounts, the withdrawal of the federal court from the management of DMR's system of services heralded a critical transition period during which thousands of citizens of the Commonwealth would eagerly scrutinize the DMR's activities. What has happened?

We have identified five changes in the system of services for persons with mental retardation since May 1993. Only one of these changes is directly attributable to the disengagement of the court. The other four changes represent significant policy and management changes launched by DMR that are, arguably, examples of the new leadership and service innovation that DMR can now demonstrate because of its independence from court supervision. These changes are also viewed by DMR as evidence of its efforts to incorporate the best of state-of-the-art national trends into the management of services for persons with mental retardation, particularly with respect to the focus on "outcomes" for consumers of DMR rather than on "process of service" indicators.

The members of the Governor's Commission are not inherently skittish about changes being made in the service delivery system. Obviously, changes are usually instituted to enhance the quality of services, to achieve cost-efficiencies, or to enable a greater number of persons to be served. We also recognize that new models of service delivery for persons with mental retardation are being proposed across the country which may ensure a higher quality of life than available currently. For some, however, any changes in service delivery systems are viewed

cautiously or, indeed, suspiciously. Thus, the phenomenon of change engenders mixed reactions. The changes we discuss below are representative of the types of perturbations in a system of services to which many constituencies of the DMR react. As is abundantly evident, the DMR is often criticized *if any changes are made* or criticized if *too little change* is observed.

Staffing Patterns in State Institutions

At the earliest possible date following the disengagement order, the DMR changed the policies by which staffing levels at the five state institutions are determined. This change affected the 2,294 individuals residing in the institutions.

Since 1986, institutional staffing levels were determined by a court-sanctioned "Single Standard Methodology " (SSM) which was based on a needs-based formula applied uniformly to each institution. Under the SSM, the average staffing ratio of the Massachusetts facilities in 1993 was 3.10 to each resident, making Massachusetts among the most heavily staffed institutional systems in the nation. In contrast, in 1992, the national average was 2.08 staff to each person.

In November, 1993, the DMR announced institution-specific staffing patterns in lieu of the "Single Standard Methodology." According to DMR, its purpose in altering the method by which staffing levels were set in each institution was to bring Massachusetts facilities in line with national norms and patterns. DMR also argued that the new staffing levels would still ensure that the unique needs of individuals living in a given facility were met.

The result of the staffing changes was a 4.8% reduction in the total number of professionals and direct care staff deemed required in the state institutions. According to the DMR, 243 FTE positions were eliminated across the Dever, Fernald, Monson, and Wrentham State Schools in 1993. The expected cost savings were also a driving force that fueled this action. According to DMR, however, "the vast majority of (saved) resources went to budget shortfalls, inflation, and unfunded mandates. A few consumers got served in the community off of the waiting list." The resultant staffing levels are still above the national norms. Specifically, the current staffing ratios at Dever State School are 3.2 to 1, at Fernald are 3.4 to 1, at Monson are 3.0 to 1, and at Wrentham are 2.7 to 1.

No independent, systematic analysis has been conducted on the impacts of the reductions in staff on the quality of care of individual residents of the affected facilities. While all the facilities have continued to enjoy Title XIX certification (the problems at the Fernald State School are discussed separately below), most observers agree that certification status is a *minimal* measure of quality of care.

Expansion of the Medicaid Home and Community Based Waiver Program

In July 1993, DMR announced the approval from the Health Care Financing Administration of its plan to expand significantly the number of persons with mental retardation living in community based settings whose services would be eligible for partial federal reimbursement under the Medicaid Home and Community Based Waiver Program. The importance of this expansion is obvious and directly felt. In 1992, the waiver program covered approximately 2,800 individuals and recovered \$37 million in federal dollars. In the new program, *by FY 1991, more than 7,500 individuals may be served and up to \$200 million in federal support recovered.* In the waiver program, residential services, day programming, respite care, and transportation services are all covered.

A strong incentive for seeking an expansion is the realization of major increases in federal funding for services provided at the state and local level. Obviously, an expected result of such increases in federal funding is the opportunity to then redeploy "saved" state funds to provide critical services to the thousands of citizens in Massachusetts who continue to be on waiting lists for services. If this result were, in fact, obtained, progress towards an important policy goal would be achieved. This policy goal is to shed the current distinctions between the 5,409 "class clients" in Massachusetts who enjoy an entitlement for services in perpetuity and the approximately 16,294 "non-class clients" who are eligible for services.

Reforms in licensing and quality control procedures

In January 1994, the DMR instituted broad reforms in the procedures used to license community based programs. The primary vehicle used by the DMR is the Quality Enhancement and Services Tool (QUEST), developed to *II evaluate the impact of services on the quality of life of individuals served.* Certification of services is now based on the QUEST results for specific agencies. As noted by the DMR, *"the DMR Contract Division is working closely with OQE (Office of Quality Enhancement) and other state agencies to develop a system that will directly link QUEST outcomes with the contracting process. The anticipated result of this direct linkage is to more clearly elucidate for private and state-operated agencies the outcomes, and the quality of those outcomes, that DMR desires to purchase. The goal is to base contracting and recontracting decisions on explicit production of those outcomes."*

The implementation of QUEST procedures has experienced a range of problems. Some of the problems were described in DMR newsletters and others were discussed in the preliminary report from the House Post Audit and Oversight Bureau issued in December 1994. These include the degree of consistency across evaluators in the use of the QUEST, the pace at which agencies are being evaluated using the QUEST, and the linkage of QUEST results to corrective actions and/or investigations of situations which may lead to abuse or neglect. As a method for the assessment of the quality of services for persons with mental retardation, however, the QUEST tool has received a national award.

Problems at the Fernald State School

In the summer of 1994, the Fernald State School came under intense professional and public scrutiny regarding its standards of care. Title XIX certification was in jeopardy based on surveys conducted by the Department of Public Health and the Health Care Financing Administration. Reductions in staff assigned to the Fernald School Activity Center resulted in numerous complaints regarding diminished services. Implementation of the "Saunders Model" as a new method for delivering services and supports to residents created considerable turmoil within the facility as staffing levels were reduced and roles were changed.

The net result of these difficulties was the perception, among some, that the "troubles" at Fernald were attributable in some way to the effects of Court disengagement. To others, some of the troubles were not attributable to current management or current DMR activity, but were, rather, part of the general legacy of inhumane treatment to which persons with mental retardation are vulnerable. To others, the Title XIX certification problems were a consequence of the facility-wide shift to the Saunders Model.

As a result, staff and members of the Governor's Commission on Mental Retardation have directed considerable attention to monitoring the management of and quality of care provided at the Fernald State School. Monthly, on-site visits have been made since July 1994.

Renewed Attention to the Growth in Numbers of Individuals on the Waiting List for DMR Services

As noted earlier, there is a general hope and expectation that the DMR will be able to reduce the size of the current waiting list for services. At the regional and area office level, the dire straits of many families and individuals on the waiting list for residential and/or day services is well known and a painful daily reminder of the need to provide greater access to services.

One of the top priorities of the Governor's Commission on Mental Retardation has been the steady articulation of concerns about the needs of unserved and underserved persons. These numbers have now been more widely circulated, a major public hearing on the issue was held in June 1994, a report was issued by the Governor's Commission in December 1994 (Strategies for Reducing the Waiting List for Services from the Department of Mental Retardation in Massachusetts) and planning for resolution of the problem has begun.

IV. ISSUES AFFECTING THE QUALITY OF SERVICES IN MASSACHUSETTS

Definitions and experiences of "quality services" vary among the many constituencies of the Department of Mental Retardation. The spectrum of opinion about the quality of the current system is vast, including:

- constituents who are pleased with the services received by their family members and who credit the DMR with the provision of innovative and responsive services and want to continue these same services,
- constituents who are dissatisfied with the conduct of DMR and who perceive the DMR as retreating from, or never achieving, the quality of services to which persons with mental retardation are or should be entitled,
- constituents who await services and who are becoming increasingly demoralized and angry as they wait--for them, they wish they had services to evaluate,
- constituents, primarily providers, who wonder how long they can continue to be in the business of serving people with mental retardation without past due, major adjustments in their compensation.

The complicated web of constituent groups to which the DMR is responsible is impressive. Each assesses the quality of the system from its own or from an individual vantage point, which renders any summary statements about the " quality of the system " either irrelevant to their individual experiences or inconsistent with their personal histories.

Among the criteria on which there is general agreement, however, are two key points. These criteria are:

- **Every person with mental retardation should have unimpeded access to services that ensures a good quality of his/her life.**
- **There should be stability in the system of services that ensures continuity in services over time.**

Access to services

On this criteria, the system is *woefully inadequate*. The Commission is aware of the growth in the numbers of persons on waiting lists for services and in the growth in the numbers of persons who are underserved. For these substantial groups, access to services is a hollow phrase. Because of the fiscal constraints that effect DMR, the number of people who cannot be served, but who have equally compelling needs as those already in the system, continues to grow dramatically.

Continuity in the system of individualized services

A well-functioning system of services should provide assurance that once an individualized service plan is in effect, it will remain in effect until reasoned analysis indicates that changes are needed. The basic mechanism for the individualized identification of service needs is the Individual Service Plan (ISP). By DMR regulation, the ISP for each person should be reviewed annually.

It is critical to remember that persons served by DMR are typically service recipients for the duration of their lives. The DMR operates a long-term care system, in contrast to many other human service agencies whose consumers may need assistance on a periodic or time-limited basis. Both the perception of instability and the experience of unwarranted change can be extremely depleting to those who rely on the state for continuing, fundamental support.

We have heard testimonials about consumers and their families being warned that they might experience a reduction in services. We have been told that DMR case managers--the most immediate link between the power of the state and the citizens who seek state services--have been instructed to "water down" Individualized Service Plans because of fiscal constraints. We have listened painfully to accounts of consumers and their families who have been warned that their futures were in jeopardy unless the legislature did thus and so. These worries affect consumers differentially. But the effects on "the system" are pernicious, for they call into question the basic functioning of government and the assumption of equality and fairness on which our democratic institutions rest.

Independent Evaluation of DMR Services

Seaside Education Associates recently released the results of its independent review of DMR services based on a four-year study of over 900 service recipients. One aspect of their analysis is particularly noteworthy:

In general, the concerns identified are characteristic of a large service system endeavoring to implement a person-centered service philosophy in what has been historically a program-centered operating environment. The person-centered goals and objectives detailed in the Department's Mission Statement appear to not have been successfully supported by the current community service system--one designed in the 1970s to provide an alternative to institutionalization rather than person-centered services. During the past when the measure of quality remained providing an alternative to the institution, the current system achieved its goal, however, when measured against current quality of life standards, the present system fares less successfully.

Their report details a litany of deficiencies in the quality of services received by individuals with mental retardation. Detailed recommendations to the Department were presented in five specific areas to address systemic change:

- program development and implementation (including residential work and day and individual supports programs), policies regarding medication monitoring and behavior programming,
- ISP regulations and practices,
- service coordination, and
- staff training.

Staff from the Governor's Commission on Mental Retardation reviewed and commented upon the recommendations of Seaside Education Associates and the DMR Office of Quality Enhancement staff in the development of the recommendations. All the Commission members received a copy of the full report. We believe that serious attention to the recommendations offers the best opportunity for DMR to advance the process of bringing reality in line with the goals the DMR has promulgated for citizens with mental retardation.

It is clear that the deficiencies in the system are not attributable to a single, isolated cause. It is also clear that the findings of the research suggest that the array of residential and day programs in which thousands of persons with mental retardation are served are not meeting the professed goals of the Department or representative of state-of-the art care. There are many notable examples of "flagship" programs across the state that are innovative, progressive, and successful in providing high quality services. The programs reviewed by Seaside Educational Associates, however, may be more illustrative of the "fleet" of programs.

Nationally, the highest standards of care are designed to promote individual supports and services, personal choices for consumers of services, use of community resources and support, capable of finding a balance between protection from harm and the pursuit of individual independence. The shift in services from a program base to an individualized supportive service base is a difficult transformation for any state system. To achieve these goals, DMR will continue to need adequate financial support from the state, the "green light" to experiment with new models of services and supports, and courageous leadership at all levels.

The Governor's Commission on Mental Retardation acknowledges that a publicly supported service system requires accountability about quality. While standards for " quality " continue to be debated, there is little disagreement that a service delivery system with major responsibility for some of the state's most vulnerable citizens must provide for quality of care. The Governor's Commission will continue to actively monitor the service system that should enrich the lives of those entrusted to its care. We will also continue to encourage public discussion and debate on proposed policy directions, provide follow-up on innovative ideas, and provide guidance and leadership to policy makers and planners.